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ABSTRACT

Participants from five states (Colorado, Minnesota, Virginia, Washington, and Wisconsin) met to establish a national network to promote state and community-based models of comprehensive coordinated planning and service delivery to adults who survived pediatric disorders in their childhood. Results of state caucuses, which discussed and listed individual state strengths, weaknesses, focus, roles of the private and public sectors, and goals and activities, are outlined. Additionally, recommendations of focus groups are listed, covering the following topic areas: (1) financing; (2) private sector; (3) public sector; and (4) community service linkages. Also identified by conference participants were technical assistance needs of their states. The conference agenda and the participant list are appended. (DB)

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YOUTH IN TRANSITION: DEVELOPING APPROPRIATE SERVICES FOR ADULT SURVIVORS OF PEDIATRIC DISORDERS

May 25-26, 1988
Baltimore, Maryland

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YOUTH IN TRANSITION

Summary of Proceedings

May, 1988

Prepared by Pam Berg

For

The National Center for Youth with Disabilities
&
The National Center for Networking Community Based Services

Funded through a grant from the Bureau of Maternal and Child Health and Resource Development; Division of Services for Children with Special Health Needs Department for Health and Human Services

CONFERENCE PURPOSE AND OBJECTIVES

Many more children are surviving pediatric disorders and reaching adulthood, in part, due to advances in health care technology. Because this is a relatively new phenomenon, the traditional adult health care system may not have the knowledge or experience necessary to provide adequate services to these young adults. As a result, many young adults with disorders such as cystic fibrosis continue to receive care in a pediatric setting. This impedes adolescents' and young adults' development towards independence.

This working conference brought together delegations from five states to develop strategies insuring transition to adult health care for survivors of pediatric health disorders. Participants from the five states (Colorado, Minnesota, Virginia, Washington and Wisconsin) included the Director of Services to Children with Special Health Needs Program (SCSHN), a physician from the adult and the pediatric community and an adolescent or parent. The initial purpose of the conference was to establish a national network that would promote the development of state and community-based models of comprehensive coordinated planning and service delivery for youth with disabilities and their families.

Other objectives were to:

- Facilitate the dissemination of materials, resources, information and technical assistance for states and communities,
- Provide for an exchange of information among states and,
- Facilitate collaborative interagency planning at the state and community level.

SUMMARY OF STATE CAUCUSES AND WORK PLANS

States met as a group to discuss and list their strengths and weaknesses relevant to the development of appropriate adult health services, and their individual state focus, goals and activities. Each state's discussion and work plan is summarized below.

Colorado

Strengths

1. Interagency task forces such as Child Find and 99-457 are active.
2. There are existing interdisciplinary teams in pediatric specialty clinics and a growing interest in coordinating adult care with pediatrics.
3. Strong parent groups are already established.
4. Four state departments have signed a transition policy statement.
5. Colorado has a history of working together.

6. The Society for Adolescent Medicine and the Department of Adolescent Medicine at the University of Colorado Health Science Center and Children's Hospital are excellent resources.

Weaknesses

1. Individuals and programs are geographically isolated.

2. Health care systems don't encourage families to be case managers.

3. Families are not empowered; they are talked to, not talked with.

4. There is a lack of communication between tertiary and primary care providers.

5. Many medical services are obtained out of state.

6. The focus of many state agencies and parent groups tends to be on younger children.

Focus

1. The Rocky Mountain Research and Training Institute will provide training and technical assistance to the following target groups: Public Health Nurses, Special Education Directors, Adolescent Clinic Staff, etc.

2. A planning group for a state wide conference on transition will be organized.

3. Encourage consumer participation on the Advisory Council on Adolescent Health and the State Interagency Transition Advisory Committee.

4. Contact Peak regarding the scope of their parent workshops on youth in transition.

Potential Roles for the Private Sector

1. Plan a training conference on transition issues sponsored by The Society for Adolescent Medicine.

2. Coordinate public and private standards of adolescent health care through an appointed task force of public and private providers.

3. Emphasize the importance of counseling about psychosocial issues in addition to counseling about disabilities.

Potential Roles for the Public Sector

1. Work with a coalition to create a high risk insurance coverage pool for individuals with conditions like aids related complex and hemophilia.

2. Provide input into the Advisory Council on Adolescent Health Care on issues of youth with chronic disabilities and illnesses.

3. Provide education about transition issues to two targeted parent groups

Goals/Activities

1. Identify two strong parent groups, contact them and evaluate their awareness of the transition period that their children will go through from school-age to adult life. Enlist leadership in the parent community.

2. Work with the Rocky Mountain Regional Chapter of the Society for Adolescent Medicine to focus their annual educational conference on the transition issues of youth with chronic illness.

3. Identify strengths, weaknesses, and gaps in adolescent services provided through pediatric disease specific specialty clinics at the University of Colorado, Denver General, and the Children's Hospital in relation to the transition to adulthood.

4. Identify, at the school level, adolescents with medical and physical disabilities who are not identified through Special Education Programs. Determine number, what services are available to them and taken advantage of, and assess their needs.

5. Identify adolescents, young adults and parent consumers to become active on adolescent advisory committees.

6. Organize a working task force to identify health care standards for adolescents and pre-adolescents with chronic disabilities . Also identify potential public and private funding resources.

Minnesota

Strengths

1. Many community options are available to adolescents and families through social organizations.

2. Health care professionals and parents are able to work with school systems.

3. Parent advocacy groups in Minnesota are well developed.

4. Health care financing is comparatively good (Medical Assistance).

5. Tertiary medical facilities, namely rehabilitation hospitals are available.

Weaknesses

1. Care is fragmented and lacks the coordination between services to make it work for the individual.

2. An extremely competitive health care environment makes cooperation difficult.

3. There is a lack of training at the medical school level, fellowship level, and throughout the medical system regarding roles on the interdisciplinary team.

4. The medical model of cure versus care is not developmentally oriented.

5. Parent and staff expectations of a child or adolescent with a chronic illness or disability may delay an individual's developmental progress.

6. There is limited coordination of programs linking adolescents' transition to vocational services.

Focus

1. Maternal and Child Health and Medical Assistance coordination around funding issues.

2. Promote young adult's transition from school to coordinate with vocational transition.

3. Educate the media, educators, and health care professionals about the transition issues.

4. Facilitate independent living for young adults with disabilities or chronic illnesses by increasing the availability of adapted housing and personal aides.

5. Develop more effective communication between health professionals who provide pediatric and adult care.

Potential Roles for the Public Sector

1. Increase overall awareness and knowledge about transition issues by offering presentations at workshops, conferences, Grand Rounds at University of Minnesota, Minneapolis Children's, and St. Paul Children's Hospital.

2. Education of medical professionals via Continuing Medical Education about the impact of chronic illness on adolescent development and the need for sensitivity to family and adolescent transition issues.

3. Collect data about jobs for youth in transition.

4. Create systems of communication and collaboration between adult and pediatric health care systems.

5 Develop standards of care which incorporate transition issues.

Potential Roles for the Private Sector

1. Form a committee of persons from various sectors to look at job issues for youth with chronic illnesses or disabilities.

2. Establish an ad hoc committee within the Services to Children with Handicaps Program to study transition to adulthood.

3. Integrate the care of students with chronic illnesses into existing school-based clinic services, for example, peer counseling for students at school clinic sites.

4. University Affiliated Program can serve as a resource for information, preparation of materials for education, and preservice training about issues relating to youth with developmental disabilities.

5. Collect data about jobs for youth with disabilities.

6 Explore Supplemental Security Income and Medical Assistance rules in order to remove disincentives to employment, marriage, and independent living.

Goals/Activities

1. Someone with expertise in "transition issues" will contact the Department of Human Services to insure adequate input into Health Span.

2. Find out who at the Department of Human Services deals with funding for equipment needs.

3 Obtain information on the State Transition Interagency Committee.

4. Explore the possibility of establishing a subcommittee on Transition Issues within the Minnesota Chapter of the American Academy of Pediatrics.

5. Identify someone within the Minnesota Medical Association who can involve physicians in the issues of insurance, financing and other transition issues.

6. Discover where the medical system breaks down for adolescents and young adults.

Virginia

Strengths

1. The state Services to Children with Special Health Needs Program is strong.

2. The University of Virginia has a possible model for transition.

3. The Woodrow Wilson Rehabilitation Center and Independent Resource Center are resources that promote independent living.

4. There is a free computerized information referral network available to the public.

5. The Division of Rehabilitation Services has linkages to Mental Health.

Weaknesses

1. For those over 21 with chronic illnesses, care is only covered for those with cystic fibrosis or hemophilia.

2. There is a lack of adult services for survivors of pediatric disorders.

3. There is a lack of community services for adolescents in transition to adulthood.

4. There are not well established standards of care for youth in transition.

5. Although many services are offered for youth, they may not adequately prepare the young adult to meet the challenges of transition.

Focus

1. Consider how clinics provided by Services for Children with Special Health Needs (SCSHN), formerly Crippled Children's Services, can be altered to address transition. Identify transition issues and develop solutions.

2. Begin developing adult services with coordinated medical and rehabilitation services. A demonstration project for transition with a center wide generic program that incorporates pediatric and adult services is one possibility.

3. Develop standards of care, especially for home care.

Potential Roles for the Private Sector

1. Motor vehicle insurance may have a role in increasing the availability of care for children injured in accidents by developing a no-fault approach.

Potential Roles for the Public Sector

1. The University of Virginia must work collaboratively with SCSHN to make the tasks detailed in focus 1 & 2 possible.

2. The legislature must appropriate funds to provide services to young people as they become adults.

Goals/Activities

1. Organize a task force on transition at the state level to write a letter to request an audience with Secretary of Health and Human Services at the state level. Explore a state task force involving Education, Vocational Rehabilitation., Welfare, Mental Health, Public Health, Department of Vocational Rehabilitation, Medical Schools, State Chapter of the American Academy of Pediatrics,Virginia Medical Society, Consumers for Independent Living Centers, and Vocational Educational Counseling.

2. The University of Virginia will develop a plan for transition services.

3. A pilot project to address the transition needs of youth at SCSHC clinics at the Children's Rehabilitation Center.

Washington

Strengths

1. There is a case management system with no age eligibility barriers.
2. The problems and needs of this population have been identified in studies.
3. There is an effective coalition for the legislative process.
4. Medical Assistance personnel at the administrative level are willing to work with other systems to serve individuals.
5. The Washington Alliance for the Mentally Ill disseminates information about existing programs.
6. There is an awareness of adolescent transition issues.

Weaknesses

1. Coordination and communication among agencies and institutions is limited.
2. Service programs at state and federal level are categorical, with no fiscal responsibility, or coordination with others.
3. More community health nurses are needed.
4. The Department of Vocational Rehabilitation needs to expand their programs, training and focus to accommodate new populations.
5. Schools and the health care system need to increase the life skills training that they provide.
6. Young adult patients with AIDS are not recognized as a part of this population.

Focus

1. A grant has been submitted to the Bureau of Maternal and Child Health for the development of an inpatient transition project .
2. Pursue the development of a community based system with The United Way, The Department of Vocational Counseling, The Washington Alliance for the Mentally Ill, The Developmental Disability Planning Council, and Seattle Public Instruction.

Potential Roles for Private Sector

1. Involve state private agencies such as the United Way, March of Dimes, Seattle Sea Hawks, Governor's Office, Research Foundations, Independent Living Centers, Disabled Youth, and Head Injury Foundation in transition issues.

Potential Roles for the Public Sector

1. Involve public agencies such as the Developmental Disability Planning Council, Washington Alliance for the Mentally Ill, Department of Vocational Rehabilitation, and Seattle Public Instruction in transition issues.

Goals/Activities

1. Plan a meeting of identified state groups to study the feasibility of a community-based transition program.

2. Follow-up of the University and Children's Hospitals Special Project of Regional and National Significance (SPRANS) transition project when the outcomes are known.

3. Continue services to youth in transition in existing adolescent programs.

Wisconsin

Strengths

1. An interagency liaison committee exists that examines various issues.

2. Milwaukee has a transition model for adolescent health care within a community clinic where young people move to the adult system. This model could be adapted for adolescents with disabilities.

3. Mandatory education laws require that districts refer children with developmental disabilities to appropriate mental health or developmental disabilities services at age 16.

4. There is a strong county idea of running services the way the county wants.

5. Currently different groups are looking at implementing community-based care. Coordination services/case management should not be limited by age.

6. Children who are in the regular classroom may qualify for special education services.

Weaknesses

1. More communication is needed between public agencies and the private sector.

2. There is a lack of knowledge regarding the needs of each community in the area of adolescent transition and uncertainty about what services already exist.

3. The state has no comprehensive public health plan.

4. There are inadequate monies to provide services.

5. Surveys of communities report the need for more psychosocial services in the areas of medicine, education and social services.

Focus

1. Survey three groups of state consumers to assess the transition needs of adolescents and parents. The groups will consist of those seen at the University of Wisconsin Hospital Pulmonary Center, those at the Milwaukee Community based adolescent clinic, and those in four counties that are currently a part of a SPRANS project in Wisconsin developing models for community-based care.

2. Present data to the State Secretary of Health in order to get transition issues included in the Wisconsin State Public Health Plan in 1989.

3. Develop school education programs that teach adolescents how to take charge of their health needs.

4. Provide inservices on transition issues to vocational rehabilitation counselors and others.

5. Work with insurance plans to provide better coverage.

Potential Roles for the Private Sector

1. Solicit a private organization to underwrite the cost of the above mentioned survey.

2. Invite the University of Wisconsin to participate in the research process.

3. Discuss the development of the transition program with the Waisman Center.

4. Increase the Private Industry Council's interest in hiring youth with disabilities.

5. Involve the state wide genetics network in transition issues.

Potential Roles for the Public Sector

1. Educate the Maternal and Child Health coalition to improve their ability to lobby effectively for transition issues.

2. Obtain information from the Department of Health and Social Services and Department of Public Instruction to describe consumers and identify their disabilities.

3. Interest state agencies in sponsoring a transition conference in Wisconsin.

4. The public's awareness of state programs for adolescents and young adults with disabilities could be increased.

5. The public sector could share the cost of insurance packages with the private sector.

Goals

1. A SWATT Team (State of Wisconsin Adolescent Transition Team) will accomplish goals as described by the Maternal and Child Health sponsored conference on transition.

2. The adolescent transition issue will be written into the State Health Plan to be developed in February 1989.

3. The transition issue will be brought to the attention of an Interagency Liaison Committee for the purpose of fostering communication and program planning.

SUMMARY OF FOCUS GROUPS

Focus groups met around the following topic areas: Financing, Roles of the Private and Public Sectors, Community Service Linkages, and Family Issues. These groups discussed problems, issues and possible strategies for addressing these areas. Included in this summary are the strategy recommendations from each group.

Financing

1. Target young people aging out of health benefits, for example, those no longer covered by family insurance or public programs.

2. There is a need for a grace period to extend Medical Assistance benefits and other services to young adults for the first five years and provide an incentive to work by undoing some of the legislation or regulations on a state by state basis.

3. New initiatives are needed to develop comparable packages of services for 18-21 year olds patterned after the model developed by P. L. 99-457.

Private Sector

1. Recruit leadership within the private sector, for example, the private insurance industry.

2. Market ideas and educational services which have an impact on the curricula of professional schools.

3. Utilize the media to disseminate data and increase the public's consciousness about transition issues.

4. Increase the advocacy base by involving parents of youth in transition.

Public Sector

1. Improve general adolescent health care by training physicians in internal medicine, family practice and other specialty areas.

2. Increase the of priority of funding for interdisciplinary models of care.

3. Establish standards of care for youth in transition, determining what the minimal level of health care should be and what should be done at the federal level.

4. Develop better coordination of care between primary, secondary and tertiary levels.

5. Develop trial vocational services at the federal level to increase the independence of young people with chronic illnesses by presenting work incentives rather than disincentives, for example, the Job Partnership Training Act.

6. Write state insurance pool policies that provide comprehensive coverage of youth.

7. The Federal Agency should define adequate health care financing, and continue support by underwriting and evaluating projects at the state and regional levels.

8. States should not be free to reduce Maternal and Child Health Block Grant funds.

9. Support and build public health nurse capacity.

10. Establish a relationship between training centers and local systems of services.

11. Improve education for parents and youth.

12. Train professionals to facilitate the transition of youth.

13. Expand and develop the schools' roles in preventive health education.

14. Provide more alternatives to institutional care.

15. Use peer support models.and educational consultants with ties to health systems--(Virginia model).

Community Service Linkages

1. Issues concerning Supplemental Security Income should be addressed at the Federal level.

2. Transition specialists are needed in the hospitals.

3. Increase parental and adolescent involvement in transition issues.

4. Use adult patients as role models and support for youths.

5. Request that major advocacy and disability groups look at problems and possible solutions for youth in transition.

6. Address transition concerns to the state level.

7. Schools need to develop functional curricula and become more involved with those youth in transition outside of special education classes.

8. Increase formal linkages with businesses to secure jobs.

9. Develop family networks for employment.

10. Increase community-based services and communication among agencies.

11. Increase training of Department of Rehabilitation counselors concerning the needs of teens with chronic illnesses.

12. Increase health professionals' responsibility to educate the general public concerning the needs of teens with chronic illnesses.

13. Increase training between health professionals, schools,the Department of Vocational Rehabilitation and agencies.

14. Health care institutions can function as technical consultants to special education personnel and vocational rehabilitation specialists.

TECHNICAL ASSISTANCE NEEDS

At the closing session, participants made the following suggestions/recommendations for information and activities that would support their state efforts:

1. Study how Health Care Financing Administration (HCFA) and Supplemental Security Income (SSI) fit together.

2. States can benefit from hearing how other states are evolving in their transition efforts, and learning what has been, and is being done by education and social services.

3. Support is needed from the Bureau of Maternal and Child Health for services and policies that address the issues of transition for adolescents with chronic illnesses.

4. Send the summary of this meeting to the Federal Interagency Committee.

5. Develop a "White Paper"on Adolescent Health ("We hold these truths to be self evident.") that details the components of a system of services for adolescents.

6. Focus on financing of health care services as it relates to adolescents who age out of pediatric services.

7. Adolescent issues and transition should be a part of the agenda of the Surgeon General's Conference. Case management services must span the life cycle.

Appendix

Youth in Transition:
Developing Appropriate Services
for Adult Survivors of Pediatric Disorders

AGENDA

TUESDAY, MAY 24, 1988

7:00 - 9:00 pm *Lobby*	Registration

WEDNESDAY, MAY 25, 1988

8:15 - 9:00 am *Grand Ballroom*	Breakfast
9:00 - 9:15 *Grand Ballroom*	Welcome and Charge to the Group Merle McPherson, M.D. Suzanne Bronheim, Ph.D. Nancy Okinow, M.S.W.
9:15 - 10:00 *Grand Ballroom*	Keynote Address - Michael Alexander, M.D. "Adults Need Adult Oriented Care"
10:00 - 10:15	Break
10:15 - 11:15 *Grand Ballroom*	Pennsylvania Experience: A Report from the MCH funded transition project of the State of Pennsylvania's Department of Rehabilitation Anne Keller, M.D. Dan Schidlow, M.D. Stanley Fiel, M.D.
11:15 - 12:30	State Caucus: Small group meetings by state to assess strengths and weaknesses in relation to developing a transition plan for chronically medically involved adolescents and young adults **Colorado:** *Executive Room* **Minnesota:** *Room 308* **Wisconsin:** *Room 308* **Virginia:** *Executive Room* **Washington:** *Room 308*
12:30 - 1:30 *Grand Ballroom*	Lunch
1:45 - 3:00	Focus Groups (Workshop/Discussion): Roles for the Private Sector - *Executive Room* Roles for the Public Sector - *Room 308*

WEDNESDAY, MAY 25th cont'd.

3:00 - 3:15	Break
3:15 - 4:30	State Caucus -- Refine assessment, look at private public roles, choose focus for action planning *See above for state room assignments*
5:30 - 6:30 *Terrace Room*	Social Hour
6:30 *Terrace Room*	Dinner

THURSDAY, MAY 26, 1988

8:00 - 8:45 *Grand Ballroom*	Breakfast
8:45 - 9:00 *Grand Ballroom*	Convene group for Focus Group assignments
9:00 - 9:50	Focus Group workshops/discussions I (See enclosure for small group assisnments) Financing - *Executive Room* Linkages with Other Agencies - *Parlor A* Involving Consumers/Families - *Executive Room* Program Development - *Room 308*
10:00 - 10:50	Focus Group workshops/discussions II (See enclosure for small group assignments) *See above for room assignments*
11:00 - 12:30	State Caucus -- Develop an action plan. **Colorado:** *Executive Room* **Minnesota:** *Room 308* **Wisconsin:** *Executive Room* **Virginia:** *Parlor A* **Washington:** *Room 308*
12:30 - 2:30 *Grand Ballroom*	Lunch and Wrapup

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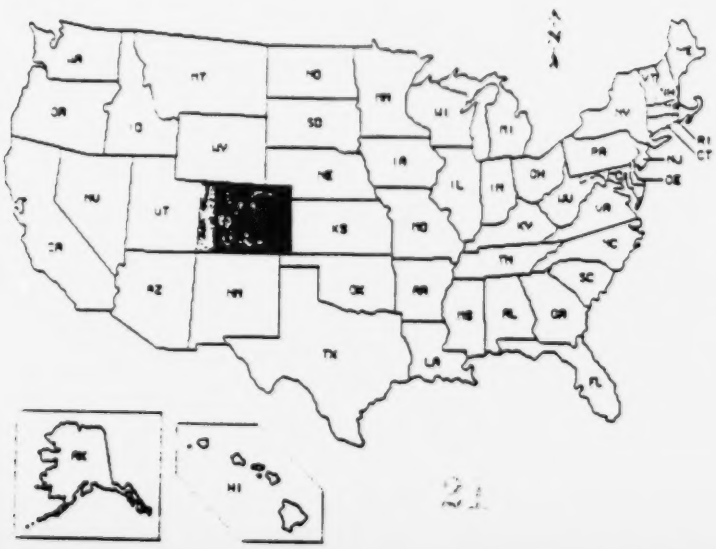

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